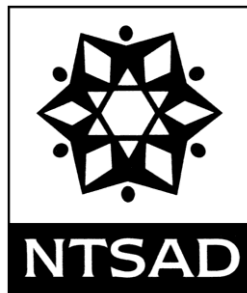


Honoring Your Loved One through Action

An NTSAD Event Guide
*From Raising Awareness to
Raising Funds in Your Community*



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Dear NTSAD family and friends:

We've compiled the [Honoring Your Loved One through Action Event Guide](#) to help us work together to make your event a success. Your interest in raising awareness in your community as well as potential funds for family services, education and research programs within NTSAD means the world to so many families and individuals struggling with these diseases.

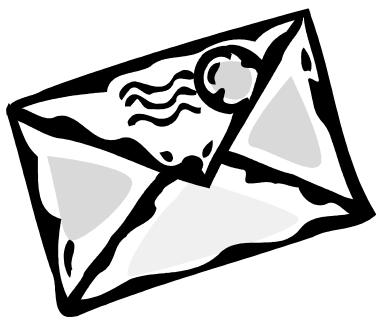
Together we can offer support for children and families affected with these diseases and at the same time raise awareness and hope for a cure! Together we can make a difference!!!

A big thank you goes to Jay Arbogast, Bonnie Davis, Tim Lord, Julie Rabinowitz and Lisa Wivell for sharing their experiences and time as we pulled this manual together.

As you think of the different ways you want to take action, NTSAD has the resources to help you put on a successful event whether it is for NTSAD's Research Initiative, the Annual Family Conference or the general fund that supports all of the programs and services of NTSAD. They include:

- Connecting with others who have done similar events
- Accessing a network of contacts who could be potential speakers and/or guests to your event
- Working with you on presentations
- Talking points for media and other audiences
- Banners & Brochures
- T-Shirts & Magnets
- NTSAD stationary
- Insurance coverage for events that require a certificate (Contact NTSAD office for details on policy and waivers)
- And of course moral support!

Should you have any questions or need assistance, always feel free to call the national office at (800) 90-NTSAD or e-mail Diana Pangonis, Communications Manager at diana@ntsad.org. We're here to help you.



Letter Campaign

A simple way to share your story, raise awareness and ultimately funds, is to send letters to family, friends, colleagues and others in your community. It is a terrific opportunity to introduce them to your loved one, your story as a family and why it is critical that they consider giving their support. For many people it is a chance to help, especially if they live further away.

The national office has templates available and can connect you with others who have done similar campaigns. There are sample letters at the back of this guide to give you some ideas.

Some tips:

1. Some families have honored their loved one's birthday by writing to their families and friends. Siblings have also used their birthdays to honor their siblings as well.
2. Write your first draft straight from the heart.
3. Step away and return to it to add the facts.
 - o Explanation of the disease. You can look to the NTSAD website for definitions, etc. The office can help you simplify it as well if you need help.
 - o The carrier statistics. Show how this disease can impact them. Many people are surprised by these numbers.
4. Where their support will go.
 - o Explain why you're asking for their support and how it will be put to use.
5. Thank them for considering making a gift and how much you appreciate their support. If you have a CaringBridge, CarePages, Facebook or MySpace page, be sure to invite them to visit it to read more.
6. Ask a few friends or even the NTSAD office to help with proofreading your letter.
 - o It's always good to get a few fresh pairs of eyes to read your letter – they inevitably offer a new perspective.
7. NTSAD can help you from crafting the letter to printing and mailing it. Just let us know!



Anyone for a House Party?

One of the easiest and accessible events to organize is what we call a “house party.” It could be as simple as a wine & cheese party, a backyard BBQ or a potluck. It is a great way to bring groups of people from work, family, and your neighborhood together to:

- a) Raise awareness about Tay-Sachs, Canavan and related diseases;
- b) Introduce them to NTSAD and how we help families and individuals faced with these diseases; and
- c) Rally a solid group of volunteers who could help with a future event that could raise funds for NTSAD's programs and services such as the Annual Family Conference, education and awareness, and/or the Research Initiative.

If you're interested in hosting a house party, here are some simple steps to put on a successful “friend”raiser. We can also connect you with others who have done a similar event so don't hesitate to reach out for guidance.

- 1. Pull a guest list together. Think about people you know at work, close friends,** acquaintances and perhaps friends of friends that may be willing to hear your story and who would want to get behind an amazing cause. Keep in mind that there might be other supporters of NTSAD in your area that you could extend the invitations to – just let us know and we'd be happy to send them an invite.
- 2. Pick a date and time.** It could be as simple as an after-work event or on a weekend for a couple of hours.
- 3. Send out your invitations.** These should go out roughly four to six weeks before the party. You can go formal and mail them or use e-mail, Facebook or Evite. If you need sample invites, contact the office and we can send you a template. Be sure to set your RSVP date a few days before your party, so you know how many to expect.
- 4. Set the program for the party.** It is always helpful to set time for folks to mingle especially if you have a mix of people from different facets of your lives. We also suggest setting time aside, maybe 15-20 minutes, to speak to your guests about why you're hosting the party, your story and your connection to NTSAD. You may even want to have a guest of honor/speaker; depending on where you live the office could help you with that detail.
- 5. Offsetting the cost.** Ask one or two friends to host the party with you to help ease the burden of expenses. You could ask a local business for a donation or at the very least a discount as well. Remember – you don't need to do anything too extravagant for the party. Keep it simple!
- 6. Have materials ready for guests to take.** The office can send you brochures, handouts and other take-away items to offer your guests to further inform them of NTSAD's

mission, programs and services. Be sure to let us know at least three weeks in advance so we can get them to you on time.

7. **Have a good time.** Enjoy mingling with your guests and sharing your story with them. It makes such a difference to hear first-hand about the struggles of families and individuals coping with this group of diseases.
8. **After the party.** Be sure to thank your guests for coming – a handwritten note is always appreciated!

Notes:



Partnering with Local Businesses In Your Community

A big thank you to Jay Arbogast for outlining his experience in raising awareness and funds in his community! Contact the NTSAD office for a detailed outline on how to connect and partner with your community.

PREPARATION / SOLICITATION

1. Contact local businesses you might like to host an event. Go prepared with a formal letter telling your story, what awareness means, and how/who proceeds will benefit.
2. Many local restaurants will grant specific days donating a certain percentage of their profits to your charity. It's often a, "I scratch your back, you scratch mine situation." The goal is for you to generate more business for them, while they in-turn donate a certain percentage of their profits to your organization.

BACKGROUND EXAMPLES

CHILI'S RESTAURANT (Chili's Night)

A flyer is generated by the restaurant and given to you to print from your home computer. Your job is simple; get the flyer to as many friends, family, co-workers, etc. as possible. Send out emails advertising the event, and attach the flyer. On specified evenings, Chili's donates 10% of their profits from all those who presented a flyer. The more flyers - the more mouths eating - the greater your success!

Now, 10% isn't a whole lot, so don't expect too much money to be generated by a Chili's Night. With that aside, it's a great way to galvanize your community. Get your neighbors involved and make it fun. We did it for an entire month, honoring National Tay-Sachs Awareness Month, last September. Our neighbors looked forward to every Tuesday that month! It opens the door to more conversation about other events you might be considering down the road. It's a great networking opportunity, and it's really easy to do because it virtually drives itself. The hardest part is the constant reminders to eat at Chili's on the said night (not too difficult)!

PEET'S COFFEE AND TEA (Peet's Holiday Fundraiser) offers annual holiday fund-raisers. (You might have caught the story in the Winter Edition of *Lifeline*.) 23 years ago, Peet's established their "Holiday Fundraiser" program. Since its' inception, they've managed to raise over \$204,000 to support more than 160 non-profit organizations. If you don't have a Peet's in your area, contact Starbucks, or another business to inquire if they might have similar programs.

For an entire week before Christmas, two Peet's locations informed patrons to join them in support of their Holiday Fundraiser benefiting NTSAD and the CTSF. Instead of asking for donations prior to the event culminating on December 24th, they would ask

customers if they would like to round their purchase to the next dollar. On Christmas Eve, free drip-coffee was offered all day, and donations were requested in lieu of tips. At the end of the day, Peet's corporate offices matched up to a max of \$1,000 of each store's contributions. This was another very easy fundraiser, but unlike the Chili's Night, it generated a lot more proceeds – over \$4500 and it virtually drove itself!

PREPARATION/HOW TO

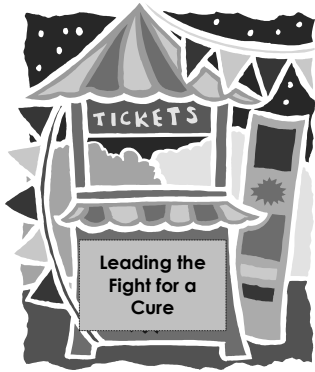
1. Contact your local Peet's shop well before the holidays as there might be stiff competition with other local non-profit groups vying for their support
2. If you have to apply at a later date, become a frequent patron of the store if you're not already. If they already know your friendly face, they'll be more attached to you and your story.
3. Once approved, plan time to introduce yourself to the staff at your supporting location.
4. Request brochures from the non-profit you're supporting. Have them ready to give to the staff, as well as to display on the day of the event.
5. Get the staff even more excited to help by getting everyone T-shirts!
6. If you have magnets, or other free SWAG, give it to your team as well. The object is visibility!
7. Finally, on the day of the event, make yourself available to answer questions from patrons/contributors. We touched a lot of hearts on Christmas Eve, and their donations were proof of that!

Advertising & Follow Up

1. Prior to whichever event you're planning, send out periodic reminder emails to friends, family, and co-workers.
2. Advertise your event by posting flyers at coffee shop bill-boards, car windows, inter-office emails, and reminder emails to friends and family etc.
3. Soon after the event, send out another mass email update thanking all those who were able to attend, and those who contributed to the success of your event.
4. Write a formal thank you to the entity, and individuals who sponsored your event and send a tax-deductible receipt if applicable.

It only takes one person you might have spoken to, either by email, solicitation, or at the actual event who might become an important future ally. Some people have great contacts, and if you're passionate about telling your story, someone will be passionate about listening. And that person might become instrumental in helping lead you to future awareness opportunities, or larger donors. Don't be shy to tell your story to anyone – that's your key to success!

NOTES:



Awareness Booths

While we work toward finding a cure, we continue to raise awareness about the risks of being a carrier and how easy it is to be screened. By setting up a booth at a local fair or festival gives you the chance to introduce people to these diseases, your story, the carrier risks and the potential of current research. The office has prepared talking points for past events so call to get them for your event as well as a more detailed outline of putting together a booth.

Sharing your story is the most compelling way to convey the message of hope and the importance of carrier screening.

A big thank you to Jay Arbogast for outlining his experience in raising awareness and funds in his community! A detailed version is available at the national office.

Preparation

1. Register Early for local fairs and festivals.
2. Contact Civic Center/City Offices for Local Fair/Festival Registration forms
3. When registration is approved, send out mass emails to friends, family, co-workers, and/or potential contributors as a first line of advertising for your event.
4. Make a list of raffle baskets, and make a list of potential merchandise contributions and contributors.

Solicitation

1. Write solicitation letters
2. Write a simple, easy to remember, solicitation that you can recite when approaching potential contributors/local businesses.
3. Make a list of all business you've contacted, include the contact name, phone #, email addresses, and most importantly a follow up date.
4. Think of personal contacts in specific lines of work that might be able to help with supplies, materials, or other connections to help ease out-of-pocket expenses.
5. Write solicitation letter for donation of materials specific to your raffle basket production well in advance.
6. **Keep out-of-pocket expenses to a minimum!**

Booth Preparation

1. Stock the booth with donation jars, informative literature and brochures, T-Shirts from NTSAD, "SWAG" (Stuff We All Get) ie. Frisbees, Water Bottles, Water Bottle Sleeves, etc.), raffle tickets, a large sign to advertise, poster board thanking all local business contributors, and a contact sheet and pen available for those who might want to

leave an email address to find out more on how they can help in the future. This can help build your local team of supporters.

Advertising & Follow Up

1. Along the way, send out reminder emails to friends, family, and co-workers of your event.
2. Keep a list of all who've contributed so you can send a formal thank you, and tax deductible receipt.
3. Advertise your event by posting flyers at coffee shop bill-boards, car windows, inter-office emails, and reminder emails to friends and family etc.
4. Soon after the event, send out another mass email thanking all those who were able to attend, and those who contributed to the success of your event. Don't be shy to tell your story to anyone – that's your key to success!

Notes:



Organizing a Community Walk

A walk is a terrific way to bring your community together to raise awareness and funds for a good cause, and, to honor those who fight and have fought so valiantly against these diseases. Remember to do what is comfortable and realistic to carry out.

Pull together friends, family members and work colleagues. To help with the many facets of a walk, bring a committee together to take on different tasks. Hold your first meeting to:

- Pick a few sites and make plans to visit them; (see next item)
- Create a timeline;
- Outline the schedule of the walk (registrations, start time, end of walk activities)
- Compile a mailing list as well as an e-mail list;
- Division of tasks along the timeline; and
- Be sure to meet regularly in order to stay on task.

Choose site. Look at your local parks, a school track, or your own neighborhood. Map out a rough route and how long it would be. Don't forget to ask your town/city about permits needed to hold a walk in the area you're interested in. If the route you choose crosses any streets you may need police detail to help with the traffic.

Secure a date. Be mindful of the possibility of rain and weather during that time of year. Also consider holidays and other major events in your area.

Save the Date! E-mail your friends, family members, their friends, and work colleagues a Save-the-Date announcing where and when the walk will take place. Don't forget to include why you're organizing the walk and why *they* would want to participate in this walk.

Seek sponsors. Send or distribute in person letters with sponsorship forms to businesses in your community to ask them for support of your walk. Remember – with a sponsorship you can highlight your sponsors on t-shirts, banners, any printed materials and if you have a website through CaringBridge, Facebook or MySpace.

Publicity. Send a press release about your event to your local papers letting them know the purpose of the walk, your story and details of the when, where and how to register.

Secure donations of food, water, and entertainment. Don't be afraid to ask local business for in-kind donations of food, water and even entertainment. Perhaps a local radio station would be interested in partnering with you.

Have information available! Be sure to send NTSAD a completed checklist of materials you would like to have at your walk at least *three (3)* weeks before your walk.

Notes:



Concert Benefit

If you enjoy music, a beautiful spring or summer day and know others who feel the same way – then perhaps a concert benefit is for you! You could host it in your backyard or someone else's to keep it manageable. Or, if you can get a larger space donated – a local restaurant, bar or hotel – you could put on a bigger charity event. Remember – do what is comfortable and realistic for you.

Tim Rochman and his delightful family were kind enough to share the outline for their successful benefit concert in honor of Elise. This year will be their fourth!

Live Music

- Booking Bands
I personally booked most of the bands using www.myspace.com and www.youtube.com. I would use Myspace's music search engine to find any type of band I was looking for that was in our general vicinity. If I liked what I heard, I would send out a personal email on Elise and what we were trying to do. I would also cross-check each band on YouTube to see how they looked performing live (I recommend doing this).
- Sound Crew
We have a friend who donates all his sound equipment but we have to pay the hired hand for their hourly time. Not a bad tradeoff!

Silent Auction (see "Silent Auction" following this section for further information)

- We used a lady named Fern Palmer as the main go to organizer and receiver of auction goods. She is an old family friend, knows everyone in town, and will talk your ear off. I recommend finding someone like this to solicit for donated items for the auction. She also solicited local merchants and vendors for free food, sides, and drinks that would help feed the volunteers which eliminated some added expenses. My dad was able to land some high end silent auction items such as week stays at condos in Florida and a private round trip flight. I had a friend in Santa Barbara, CA that also donated a week stay at his ocean front rental. Some family, relatives, and friends also were able to find people or bring things to the silent auction.

50/50 Raffle

- We used nephews, nieces, little cute kids and maybe a couple of adults to oversee. Little kids can sell tickets. Sometimes you even get the money won donated back. So this is a win-win!

Food & Beverages

- Ask local businesses like your favorite restaurant/pizza place, Sam's Club, Costco, or BJ's to donate food and beverages. This is where having great volunteers is helpful! (Ken's Fish Fry - we have a couple old family friends that love to fish and then batter dip and deep fry bass, bluegill, and catfish. All donated for free, just add a couple of sides and you sell \$5.00 plates. Mmmmmmmmm!!!)

Other Ways to Raise \$

- Proceeds of Band Merchandise
I tell the 1st time bands that bands in the past have given portions of the proceeds from their merchandise sold at our event to our cause. They usually say yes to also doing that ☺ I also use kids to push their merchandise. A cute kid can sell cds and shirt very easy.
- Tip Jars at the bar
If you can put tip jars everywhere people are being served with signs saying what the tips are going to, people usually tip more generously.
- Special Guest \$500 and \$1000 Tables.
My dad mad many phone calls to all the people he did business with and went into salesman mode. He sold tables of 4 (\$500) and tables of 8 (\$1,000). People received catered steak dinners (it may have been a 5 course meal) with a good amount of wine to go along with it.

Miscellaneous Tips from Tim:

- Use Banners to display at event.
- Benefit Flyers to spread the word about the event.
- Media: Radio, TV, Newspapers, Internet
 - Local Radio, TV, Newspapers used to get event out to the masses.
 - Blue Sky Website has event listed in detail and photos of past events.
 - Newspapers and Local New Stations also post articles and interviews about Elise and the event on their online sites.
 - I will also be using Facebook, Myspace, and my own email contact list to promote the event and ask all my friends to help spread the word
- Volunteer Shirts - we used Ken's neon green shirts and NTSAD's purple shirts would work great too!
- Photos of Kids through out the whole event or put together a slideshow on any Big TVs located onsite.

NOTES:



How to Run a Silent Auction

(printed from www.wikihow.com)

A silent auction is always fun to attend as it brings out the competitive side in folks and the fact that it's going to a good cause only helps! It is also a terrific way to get your local businesses involved in raising awareness while getting good PR for themselves as well.

There are many components to a successful silent auction – some of which we'll highlight below. For a detailed "how-to" contact the office or reference the website above.

- Begin planning at least four to six months in advance.
- Assemble a reliable and active volunteer committee to help with all the parts.
- Collect donated Auction Items.
- Send a "Save the Date" announcement once you secure a date and follow with invitations at least four to six weeks prior to the event.
- Have a detailed schedule of the Day of Event
- Set up as early as you can
- Run through the event with volunteers before opening doors
- Consider having an Emcee encourage bidding throughout the event
- Have a solid check-out plan after auction closes
- Give thanks and recognition to those who donated items, time and money!

NOTES:



Getting Kids, Their Schools and Friends Involved

It is amazing how kids want to help and when given the opportunity they certainly know how to run with it!

There are too many different ideas to list them all, but here are a few. *Thanks to Julie Rabinowitz for sharing what she did in her community!*

Trick-or-Treat for Tay-Sachs

1. Contact principal of school to run idea by him/her.
2. Create flyer and sponsorship materials to explain the fundraiser to local businesses and to educate them about Tay-Sachs disease. Outline details about fundraiser (how kids will collect candy & change, different levels of sponsorship – per pound of candy collected or flat donations, how they will be recognized for their participation, etc.) Specify deadline for collecting donations.
3. Call, hand-deliver and/or mail materials to businesses or possible contributors. Make follow up phone calls.
4. Get school staff involved in explaining fundraiser to students a month or so ahead of time – get them excited about fundraiser, and educate them about Tay-Sachs. Send home flyer outlining event. Highlight prizes/ incentives for classes who collect most candy & change (ex. pizza lunch, ice cream, bagel breakfast, etc.).
5. Have students make posters about the event to hang around school.
6. Determine where candy will be donated (food pantry or distribution center, women's shelter, etc.) Call ahead to be sure they will accept large donations!
7. Place collection bags or boxes in all classrooms 1 - 2 days before event. Send home collection bags with the students about 2 days before event. They can use these bags to go trick-or-treating, and then to return the candy to school.
8. On the day of the event, have a candy weigh-in. Each grade or class has their candy weighed separately. Make a chart for candy totals. If possible, have winning classes announced over PA system.
9. Bring candy to food pantry, etc. (You may want to sift through all the candy first and discard all unwrapped or strange stuff!)
10. Bring change to bank (the coin machines are great!) to calculate totals.
11. Send out thank you notes to all businesses and individuals who donated, as well as to all classes who participated.

Other Inspiring Ideas

The classic lemonade stand – Mix one part hot summer day with one part ice-cold lemonade served by a bottomless source of smiles and giggles and your kids can raise awareness and funds for a great cause. Display pictures, hand out a brochure with every cup of lemonade and maybe add a cookie to the mix.

Penny Drive – Challenge the schools to collect pennies for one week or one month. Perhaps partner with a local bank and local paper to share results and your story. 'Pennies for Prevention' or 'Pennies Promise a Cure'

Bake Sale – Who doesn't love a homemade cookie? Again, this would be a fun way to raise funds in your neighborhood – perhaps add an Iron Chef component to it to get the neighbors involved.

Neighborhood Yard Sale – Why not encourage the neighborhood to lighten up for a good cause? The kids can be a great help with selling especially if lemonade and cookies are for sale too!

Involve kids' sports teams/leagues.

NOTES:



Sharing Your Story with Doctors, Medical Students and Hospital Staff

Have you ever encountered a health professional with less-than-stellar bedside manners?

Would you like to organize a screening of the “Parenting a Child with Life-limiting Illness?”

One unique way to honor your loved one is to share your story with health professionals and medical students, who are hungry for the parent perspective. It offers them the opportunity to hear a family’s first-hand experience and apply that to how they care for patients affected with these or similar diseases in the future. We can send you copies of the DVD to share with doctors, medical students and staff.

Many thanks to Desiree Hopf, Judy Kaplan and Blyth Lord for their help pulling these points together!

Tips:

- Talk to your pediatrician, primary care physician, neurologist and/or geneticist about hospital grand rounds or other opportunities to reach out to your local healthcare community.
- Consider presenting your story with your pediatrician/neurologist/primary care physician to represent both perspectives. It is beneficial to show how both the parents and the physicians can work together as a team while caring for your loved one and the whole family.
- Medical training is crammed full with clinical information and the psycho-social aspects of diagnosis, care and end-of-life issues related to children with life-limiting illness is given short shrift, and as a result, students, residents, new practitioners are eager, eager, eager to deepen their understanding.
- Contact your local medical or nursing school to explore the possibility of addressing medical and/or nursing students about genetic diseases.
- Call a local hospice to discuss not only sharing your story with staff but how pediatric hospice is different than adult hospice.

- Judy Kaplan, PSG member, shared what they did - There are several teaching hospitals in the Boston area, mostly associated with Harvard Medical School. Their Neurology departments all have information about Linda and Tay-Sachs. If the students study the disease during a semester, we usually participate in either a panel discussion with a Tay-Sachs researcher, a TS clinician and NTSAD's Executive Director, or at an end-of-training test of students. We bring Linda along so the students can see how LOTS actually presents, and so the students can ask her questions. Linda has also been used as a "Guinea pig" patient, where a single student has to identify her condition based on observation and asking questions. We give a copy of the Late Onset Tay-Sachs brochure to all doctors who we come across.
- Contact the national office to receive materials to hand-out to those you meet along the way. We can customize and personalize the information to suit your needs.



Proclamations from Your States

Another way to raise awareness is to request a proclamation from your state governor declaring a month as Awareness Month for the disease that affects your family. The month could depend on whether you're hosting an event, when your loved one was born, or even when NTSAD was founded (September).

A few things to think of when you're seeking a proclamation:

- Visit your state government's website or call your governor's office to find out what their application process entails;
- A template for a letter (see sample in the back of guide) is available through NTSAD or Ken along with informational materials to educate your governor's office;
- Remember to share *your* story in the letter;
- When you receive the proclamation, let everyone know! Perhaps your local media outlets would be interested in your story and the importance of awareness. For instance – just 1 in 250 people in the general public could be a carrier of the Tay-Sachs gene;
- Perhaps you can coordinate a house party, backyard BBQ or another event with the announcement of the proclamation;
- Let NTSAD know when you receive a proclamation so we can put it up on NTSAD's website.

NOTES:

Commonwealth of Massachusetts



A Proclamation

His Excellency Governor Deval L. Patrick

Whereas Tay-Sachs is a rare, inherited disorder that causes progressive destruction of nerve cells in the brain and spinal cord due to insufficient activity of an enzyme called beta-hexosaminidase A; and

Whereas There is no treatment or cure for Tay-Sachs disease and it is fatal in children; and

Whereas The disorder was first identified by British ophthalmologist Warren Tay in 1881 and American neurologist Bernard Sachs in 1887; and

Whereas Tay-Sachs disease often affects families with no prior history. Approximately one in twenty-seven Ashkenazi Jews and French Canadians, one in fifty Irish Americans and one in every 250 people are carriers of the disorder. If both parents are carriers, there is a twenty-five percent chance that their child will have Tay-Sachs disease; and

Whereas Through public awareness the Commonwealth of Massachusetts seeks to provide an opportunity for all people to learn more about the causes and warning signs of this disease,

Now, Therefore, I, Deval L. Patrick, Governor of the Commonwealth of Massachusetts, do hereby proclaim November 2008, to be

TAY-SACHS AWARENESS MONTH

And urge all the citizens of the Commonwealth to take cognizance of this event and participate fittingly in its observance.

Given at the Executive Chamber in Boston, this fourteenth day of November, in the year two thousand and eight, and of the Independence of the United States of America, the two hundred and thirty-second.

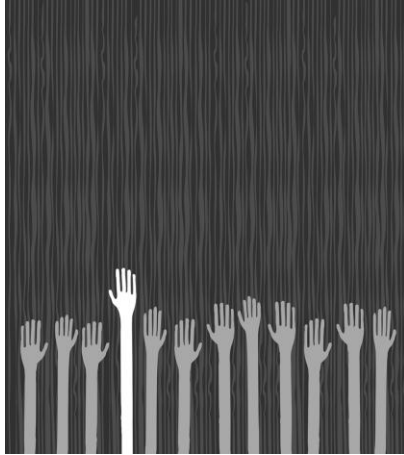
By His Excellency



DEVAL L. PATRICK
GOVERNOR OF THE COMMONWEALTH

WILLIAM FRANCIS GALVIN
SECRETARY OF THE COMMONWEALTH

God Save the Commonwealth of Massachusetts



Wait! There's One More Way You Could Honor Your Loved One...

Are you mystified by the NTSAD Board of Directors and the various committees?

Are you energized by collaborating with others?

Do you like brainstorming with a fun group of people?

Then you may want to consider helping on one of NTSAD's Board committees!

As you know, there are many facets to NTSAD and all that we do on a daily basis. Through committees, we're able to see ideas go from being shared to being realized – an invaluable process to keeping NTSAD vital!

Family Services Committee

Mentor, support, care and advocate for PSG members;

Conference Committee

Ensure the conference encompasses the needs of attendees from helpful sessions to vital childcare to the reunion it always is;

Research Initiative Committee

Usher NTSAD along the path to ground-breaking research, stay informed about research and communicate the results/updates to members and supporters;

Development Committee

Provide support for members as they plan community events, and grow and cultivate NTSAD's donor base;

Communications Committee

Develop a clear plan to communicate NTSAD's mission to the members, donors and the general public; stay current on updates to NTSAD's websites; assemble various publications including e-newsletters and Annual Report.

If you're interested in participating on any of the committees listed above, feel free to contact a member of the Board or any of the staff (Sue, Joan, Kim, Diana or Ingrid). We'd love to have you!



Tap Into Volunteers' Strengths for a Successful Charity Event

Everyone must row with the oars he has.

- English Proverb

When it comes to charity events, what's your strength? Are you a leader who's good at motivating people, or are you more of a behind-the-scenes person who makes sure everything's ready for the big day? Are you a salesperson who can ask for donations, or are you a good speaker who can move people with your story?

We all have unique strengths that we bring to charity events; this extends to the volunteers we recruit, as well. When I organized previous Alzheimer's Association Memory Walks, I found that by tapping into each volunteer's skills and abilities, my committee was more motivated and effective.

Whether you're organizing a charity event or you've signed up to participate in one as a team captain, you'll need volunteers to achieve your goals. To find them, first take out a piece of paper and write down all of the tasks with which you'll need help. For example, if you're a team captain, your list might include:

- Asking for individual donations
- Asking for donations from businesses
- Creating an email campaign and/or website for your team
- Developing signs, hats, etc. for your team
- Organizing mini-events to meet your fundraising goal, such as car washes or bake sales
- Accounting (collecting and keeping track of team members' donations)
- Logistical planning (car-pooling to the charity event, etc.)

Once you have your list of tasks, take out another sheet of paper and write down everyone who has volunteered to help you. Think about each person's unique characteristics and skills. What does she do for a living? What are his hobbies? Jot down anything that might relate to the tasks at hand.

Now start matching up volunteers with the tasks. Is one of your volunteers a member of your city's chamber of commerce? With her connections, she might be a great person to ask businesses for donations. Do you have a volunteer who is skilled in arts, crafts, or design? He might be the perfect person to create signs and a special hat or shirt for your team members to wear. Someone good with numbers would make a great accountant, while a techie could be in charge of your email campaign and fundraising website.

You get the picture. Figure out what your volunteers' "oars" are and give them license to row with them. By matching volunteers' strengths with targeted tasks, you'll increase motivation and the likelihood that your volunteers will follow through on your requests. If you don't know a volunteer's strengths or you're having trouble matching her strengths to specific tasks, ask her what she'd like to do to help. She might have a great idea that you hadn't thought of, which will make your team even stronger.

10 Tips for Organizing a Winning Fundraiser

(from CarePages.com)

Bringing people together for a good cause or to honor a specific friend or loved one is a beautiful thing. But a clear plan is key to getting the money to flow. If you're thinking about organizing your own fundraising event, consider these steps before getting started to make it a win-win situation.

Define your target audience. What type of people do you want to attract? Everyday people? Deep-pocketed executives only? Your audience will dictate the type of fundraiser to plan.

Define your event. You have so many options, from car washes to bake sales to raffles. Are you going to ask for money? Sell stuff? Hold an auction? Assess your resources and use them to your advantage. For example, if you're limited on startup costs, a neighborhood cleanup might be more appropriate than a charity ball.

Consider your overhead costs. Will it be a car wash? If so, you'll need supplies.

Get help. Ask local businesses if they are willing to donate supplies, products or prizes to help with your efforts.

Form a committee and split up tasks. Be sure to create concrete deadlines for completing project milestones.

Pick a prime location. Ask businesses if they are willing to donate space, especially if they support your cause.

Agree on a suitable time and date. Time of year can dictate a lot. For example, a car wash or yard sale might be better suited for warm weather. Attendance tends to be higher on Saturdays, but make sure to consult community calendars to make sure you're not competing with other big events.

Learn from other area fundraisers. Research other successful fundraisers in your area and learn from their best practices. What worked and what didn't?

Be creative. Consider an online component, such as creating a website for the fundraiser. If you have a CarePages website, you can advertise the event as an update and post photos from the event afterwards.

Spread the word. Advertise the event. Place signs around town, take advantage of local free weeklies, community bulletin boards and advertise on free websites like Craigslist.org. You may also want to send out an email list and encourage others to forward to a friend.



NTSAD Checklist for Materials

National Tay-Sachs & Allied Diseases Association, Inc.

Following are items NTSAD can send you to enhance your event. Please be sure to send this checklist to the national office (email, fax or snail mail) at least three (3) weeks before your event.

NTSAD T-Shirts

We'll send T-Shirts for your volunteers to where and enough for you to sell either before or during your event. Suggested pricing is \$15 per t-shirt.

Please send me: Youth Size (Small)
 Youth Size (Medium)
 Adult Size (Small)
 Adult Size (Medium)
 Adult Size (Large)
 Adult Size (X-Large)
 Adult Size (XX-Large)

**To Be Updated
for 2014**

NTSAD Magnets

Offer a chance to *drive home our mission* with these car magnets. Suggested pricing is \$3 per magnet or 2 for \$5.

Please send me: Magnets

NTSAD Custom Brochures

We have brochures that explain NTSAD's programs and services that we can customize for your event specifically.

NTSAD Annual Reports

This report is a beautiful introduction to National Tay-Sachs & Allied Diseases Association and the incredible NTSAD family.

Please send me: NTSAD Annual Report

NATIONAL TAY-SACHS & ALLIED DISEASES ASSOCIATION

A Common Bond | An Uncommon Determination

Family Services
A Commitment to Research
Public and Professional Education





NTSAD Family Event Post-Event Evaluation

**National Tay-Sachs & Allied
Diseases Association, Inc.**

Congratulations on your event! We hope everything went as you planned plus more! NTSAD appreciates your efforts to raise awareness about these diseases in your community along with raising funds for NTSAD's invaluable programs and services.

As a follow-up to your event, we ask you to consider filling out this evaluation to share your thoughts about your event, what you would do differently, what worked well and what we can do better to help with future events. We also ask that you to share your experience and photos with others members on NTSAD's Facebook page!

Name of your event:

Date and place of your event:

How many volunteers helped you with the event?

Did you have a raffle or silent auction?

- **How many items did you have?**
- **What items did you have?**

What did you raise and did it meet your expectations?

When did you start planning your event?

- **Did you have enough time to prepare?**
- **Would you give yourself more time on the next event?**

What would you do differently the next time?

What can NTSAD do better to help with future events?

Are you planning any other events in the near future and what can we do to help you?